Congratulations to Mario Bonavita (on right), winner of the 2008 Matthew Dandurand Award for Exceptional Effort. On Mario’s left is Stephen Shore, Ph.D., who presented the 3rd Annual Matthew Dandurand Memorial Fund Lecture on March 28th at the Holiday Inn in Holyoke, MA. Dr. Shore’s topic was Self-Advocacy and Disclosure for Teens and Young Adults with Asperger Syndrome. AANE thanks the Dandurand family, the other donors to this fund, and event organizer Kathy Brock. You can read more about Mario on page 8, and purchase a copy of Dr. Shore’s book Ask and Tell at AANE’s online store.

SAVE THE DATE!
AANE CAPE COD SUMMER CONFERENCE
NO MORE MELTDOWNS
with Jed Baker, Ph.D.
Thursday August 13, 2009
at the Cape Codder Resort
Hyannis, MA

Find more information soon at www.aane.org
Co-sponsored by Children Making Strides, Pocasset, MA & The Southeast Alternative School, Hyannis, MA

AANE invites you to read the
Asperger Connections 2008
Keynote Address by Daniel W. Rosenn, M.D.
at www.aane.org.

Call for Adult Artists with Asperger Syndrome
The Asperger’s Association of New England will hold an art exhibit on Saturday Oct. 3, 2009, the second day of its annual conference at John Hancock Hall in Boston, Massachusetts. All artists with Asperger Syndrome, 18 years of age and older and living in New England, are invited to submit entries. Two dimensional art, sculpture and jewelry will be accepted for consideration. Work must not have been previously exhibited by AANE. One jpg each of up to six different pieces of artwork may be submitted by no later than May 29, 2009. Please email to ktigheclark@aim.com. The AANE art committee will jury all work. Artists whose work has been accepted will be notified by June 12, 2009.

Cover: On January 31, 2009, many AANE community members greatly enjoyed seeing the model train set up of AANE member Allan Cook.
Thank you so much, Allan!

Above: Kevin Hill-Williams, Self Portrait
Dear Friends,

These are certainly turbulent times. We have major political change. We have an unstable economy. We have a new world, and international issues that are seemingly more complicated than before. We have environmental changes confronting our world in new and different ways. Yet even with all of these changes and challenges, AANE continues to thrive and perform a vital service to the community of people living with Asperger Syndrome and related conditions.

From the start—thanks to the leadership of people like Dan and Barbara Rosenn, and Dania Jekel—AANE’s mission has been clear: to help people affected by AS live happier, more independent lives. By constantly listening and responding to our community, AANE has developed into one of the leading organizations of its kind in the United States. Our dedicated staff and volunteers field a tremendous number of calls each day, run support and activity groups, and offer top-notch educational conferences and training.

Realizing that all parents and caregivers feel like pioneers at the start of the journey, AANE aims to provide services and referrals that will meet a family’s needs all along the way. As a child grows into an adolescent, and then into an adult, it is comforting to know that AANE is still here to help.

AANE is only here because of your support—the hours you have volunteered, the workshops and conferences you have attended, the experiences and concerns and resources and insights you have shared with our staff and board. As the times demand that we do more with fewer resources, we certainly need your continued support so that we can continue our work, and keep our programs and services up to date with your needs. Please continue to keep AANE in your thoughts, and stand by us as we strive to be there for you.

I hope to see you at our Gala on May 9th at the Newton Marriott, to enjoy the humor of noted comedienne Paula Poundstone, and meet Shonda and Curt Schilling, who have graciously agreed to act as honorary co-chairs for the event. It should be a fun night!

Sincerely,

Hank

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The AANE Journal is published twice a year: once in the spring and once in the fall. Please submit articles or ideas, stories or poems, drawings or photos, to the Editor, Stephanie Loo, at Stephanie.Loo@aane.org

We are so grateful to the advertisers who help subsidize the AANE Journal. For information on advertising in a future issue, please contact our Advertising Coordinator, Carynn Meyers, at Carynn.Meyers@aane.org.

Please note that articles in the AANE Journal represent the views of their authors, and are not necessarily those of AANE board or staff members. Our aim is to give you information so that you can make your own judgments and decisions.

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MESSAGE FROM AANE BOARD PRESIDENT HANK MILLER

Asperger Syndrome Trainings

The Asperger’s Association of New England is pleased to offer in-service training for educators, mental health professionals, court personnel, police officers/first responders, college staff, parents and community groups on Asperger Syndrome and related Autism Spectrum Disorders. Training ranges from 90 minutes to a full day (6 hours), and is arranged at a mutually convenient time and location. Fees vary depending on topic, presentation length, and travel time. We are always developing new topics and training can be customized to suit your needs.

For more information, or to book training for your group, please contact Robin Lurie-Meyerkopf, AANE Associate Director at:

(617) 393-3824, ext. 316, or robin.lurie-meyerkopf@aane.org.

Training topics can be customized for either introductory or more advanced groups. Below is just a sampler:

► UNDERSTANDING SOCIALLY CHALLENGED CHILDREN
► SOCIAL SKILLS: WHY AND HOW
► BULLYING ISSUES AND STUDENTS WITH AS
► MARCHING TO A DIFFERENT DRUMMER: RECOGNIZING AND SUPPORTING YOUNG CHILDREN WITH ASPERGER SYNDROME
► MAKING DAILY LIFE WORK AT HOME
► TWO-DAY TRAINING FOR ELEMENTARY SCHOOL STAFF
  Day 1: Helping the Student with Asperger Syndrome: Practical Strategies for Elementary Classroom Success
  Day 2: Developing quality, building-wide and individual supports for elementary students with Asperger Syndrome
► ADVOCATING FOR THE AS CHILD/TEEN IN PUBLIC SCHOOL
  For: Educators, advocates, or parent groups
► UNDERSTANDING ASPERGER SYNDROME
  For: Court staff/law enforcement groups, college staff, mental health professionals, community groups
► UNDERSTANDING AS (ENGLISH)
  ENTENDIENDO EL SINDROME DE ASPERGER (SPANISH)
  For: Parent groups
MESSAGE FROM DANIA

Dear Friends,

I want to thank all of you for rallying around AANE during the past anxious months. Despite everything, so many of you gave very generously to our annual appeal—thank you so much for this vital support. Many of you also came out to celebrate the launch of Michael Palmer’s medical thriller Second Opinion, and to enjoy the Ronnie Earl and the Broadcasters concert, organized by blues fan and AANE board member Steve and Barbara Garfinkle. If you missed either event, you can purchase Michael’s book, or a Ronnie Earl blues CD, from AANE’s online store. We plan to have more events like these, smaller in scale than our annual Gala, where people in our community can connect. In addition, we are so grateful to the McGovern and Fitzgerald families for hosting their annual St. Patrick’s Day road race and dinner fundraiser in Western Massachusetts, and donating some of the proceeds to AANE this year.

We have wonderful conferences and presenters coming up: Ari Ne’eman at our July conference exclusively for adults with AS, Jed Baker on Cape Cod in August, and Tony Attwood and Kari Dunn Buron at John Hancock Hall in October—all with our second exhibit of wonderful art by adults with AS. We are also very excited to be collaborating with MGH YouthCare on a conference for spring of 2010, on the highly relevant topic of anxiety in people with Asperger Syndrome.

We will recruit clinicians, academics, and researchers who can comment in depth on this important topic; we will also hear directly from adults with AS. Our professional roundtable on increasing supports for college students with AS is in the very early stages of planning a college conference, too. As Robin Lurie-Meyerkopf continues to work with chapter leadership in Maine, New Hampshire, Vermont, Connecticut, and Rhode Island, we will have more events to tell you about in areas farther from Boston—and watch your monthly enewsletter for information on webinars in 2009-2010. We hope you will come learn with us at many of these events.

We are delighted that requests for training have been pouring in—some from unexpected new places. For example, I recently did a training at the Joslin Diabetes Center. People with AS are everywhere, and AANE staff can help a variety of professionals understand how to work skillfully with them. If you work in or know of any setting where training is needed, please contact me or Robin.

I wish all of you will a good spring and summer. I hope to see you at the Gala in May, and at Asperger Connections 2009 in October!

Sincerely,

Dania Jekel, MSW
AANE Executive Director

AANE invites you to an all day summer conference exclusively for adults with Asperger Syndrome

Know Yourself
The Key to Success
with keynote speaker
Ari Ne’eman, Executive Director
Autistic Self-Advocacy Network

Saturday, July 18, 2009
at
Northeastern University

You will be able to find more information and register soon at www.aane.org.

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AANE Journal Issue 4 Spring 2009
In the fall of 2008, Dr. Daniel Rosenn was the keynote speaker for the 11th Annual Conference of the Asperger’s Association of New England. Since many people have requested a copy of his remarks, they are now posted in their entirety on our AANE website. Below are some small excerpts from his memorable talk.

...The growth of the AANE in the past dozen years has been absolutely breathtaking...And the proliferation of what the world now knows about Asperger’s—the hundreds upon hundreds of research publications, media articles, workshops, manuals, books, memoirs, experts—was unthinkable the first time we gathered...13 years ago.

But the ground floor of the AANE is not where I want to begin my comments this morning. In fact, if you will indulge me, I want to begin in the sub-basement of my experiences with AS almost 20 years before the AANE was born. I want to try to capture for you what it was like for me as a young physician, and an even newer psychiatrist, to slowly become entranced, not just in the Asperger’s diagnosis, but in the Asperger’s experience.

I am a little bemused by the fact that since my first patient with Asperger’s in 1978, I have now been involved with close to 3,300 individuals who have had Asperger’s or related disorders, from age 2 1/2 to 87 years old.

For someone who is now meandering into the vestibule of my own old age it is, I think, meaningful to pass on to you, while I still can, how I had to try, and continue to try, to piece together an understanding of this strange, lonely, and counterintuitive syndrome. This is a story of serendipity on the one hand, but also of a temperamental pull to a group of people who were disregarded and invisible, and who for decades were trapped in a medicolegal-diagnostic waste-land...

...I have always been interested in how one started and maintained a relationship. In a very serious way, it always seemed to me that the central core of healing in Psychiatry was a trusting, mutually respectful relationship between two people. Whatever the theoretical dogma...I always felt that the relationship, and what transpired within it, was a crucial part of the healing.

So for me, the issue was how to create a relationship with kids who were so traumatized, abused, emotionally injured or even psychotic, that they could not interact well enough to take part in therapeutic change. I never dreamed I would end up primarily seeing children on the autistic spectrum...

Parenthetically, Teddy and I were in therapy together for 7 years, much of it 2 or 3 times/week. In those days, insurance was incredibly generous. I learned more about Asperger’s from him than from any other single source of information since. I learned by trial and error: by watching and thinking, and trying out strategies.

From this relationship [with my first child patient with AS], came a guiding principle in terms of beginning psychotherapy with individuals with Asperger’s: Start with where the child is and gradually broaden the margins of his narrowed interests. So in the next several years, with the ever-larger stream of Asperger’s kids who wandered into my office with their bags of plastic dinosaurs, their Thomas the Tank Engines, my little Weather Announcers, Guinness Book of World Records keepers, the collectors of paper clips and cigarette butts, the Historians of the Titanic, the Star Trekkies, the map-makers and herpetologists, I always started with where they were, and was quick to be enthusiastic and interested and excited by what they were interested in. I wanted to know the details, even if by neuro-typical standards, they could be boring and repetitious.

I remember one little 6 year old who came to see me. He brought in a large hour glass, which he kept turning over to see the sand sift down. Like all the Asperger’s kids, he wanted nothing to do with my doll house or action figures. I did happen to have a small 3 minute sand-glass egg timer. We sat next to each other doing the same thing in parallel. The next week, I purchased a medium size hour glass. So at this point, we had his large one, my small egg timer glass, and now a middle size glass. You know what? We had a family of hour glasses! A Daddy, a Mommy and a Baby, and we could begin an admittedly bizarre, but at least anthropomorphic play about an Hour Glass Family. This slowly became the start of his therapy. He is a grown-up now, but I still see him for follow-up visits and medication management.

We call these maneuvers “bridging techniques.” Consequently, when new kids came to see me and, for example perseverated on drawing maps, I always managed to draw my town on the far side of the paper, and eventually draw in a connecting highway. It took a while, but from playing in parallel, we over time connected our towns and made countries and continents. We eventually had a metaphor to begin to work out how people run a country, how people get along with each other. I had what today the finance people call “leverage.”

...The second guiding principle was: Once we had found a way to bridge, the hour had to be fun. What good is it to come see some guy every week if it’s not fun? The very best bridge was some episode of intensely shared humor, a really funny joke where both the patient and I really laughed together, hard. So before we even got to the therapeutic interventions per se, I had to let the child know I liked him or her...I always felt myself drawn...to the children and adolescents with Asperger's. They looked at the world so differently. They made me re-examine what perspective-taking, imagination, and play were all about.

For example, people said that kids on the autistic spectrum had no empathy or feelings, and clearly this was wrong. They had huge reservoirs of intense feelings. In fact, they were often excruciatingly emotional, especially around certain issues, like fairness and justice. They had lots of their own feelings; it was just that many did not seem interested in other people’s feelings. People said they were not aware of subtleties of verbal expression, but I noticed my patients were incredibly sensitive to small shifts in tones of voice—they just read them entirely differently from the way I would, or the way they were intended...

They were not little robots or even, for the most part, Little...
Rainmen. Unlike the myth, many of them did tell lies, they just lied poorly and transparently. Sometimes they didn’t mean to hurt other people, and were unintentionally rude and obnoxious. But other times they did intend to lash out quite fiercely, although unreasonably, because of trivial events that usually would not have bothered other people.

Then there was the myth of empathy. At times they could be extremely caring and affectionate. They especially loved their mothers, with a deep, abiding love that could be attached only to someone who constantly stood ready to help them interact with a world they often didn’t understand, or distorted, or feared. Although they could clearly mistreat their mothers, even be quite abusive at times, there was no doubt they were often quite empathic to mothers, even to their subtle feelings.

…I discovered that people with Asperger’s do have empathy, it is just erratic. It is like Swiss cheese: it has big holes in it. You, and they, cannot rely on it being there consistently.…

But this unpredictability is especially confusing and scary to the Asperger’s individual of any age, who often is not sure how, at any one point in time, his efforts at social approach will be received. Often he or she can never quite be sure whether he will be laughed at, ignored, or accepted…

In the 1980’s I began to sort through techniques in my office that would helpful to kids with Asperger’s. All of this will seem like old hat to you, and is pretty obvious from today’s perspective. It is hard to describe how in the dark we were…[The] kids helped by telling me what was stupid or what worked. They were my supervisors. I knew that just playing chess or Uno was not enough, but lecturing or giving advice about socializing was entirely useless. And conventional play therapy, where so-called inner conflicts were uncovered and worked out in pretend play with dolls, was also ineffective.

One thing that helped was putting the feelings that the children were groping to understand into concrete diagrams, drawings, and cartoons. It wasn’t so much strong feelings like anger or pleasure that they didn’t understand, but gradations of feelings…

Everything was concrete and visual. If a child described a time he was teased on the school bus, we would drag in some chairs from the waiting room and make a pretend row of bus seats. I would be the bad kid, and with my patient’s instructions, we would play out what happened. And then we would switch roles, and try to come up with a strategy to try out, and practice role play in my office…

If the child had a few major worries that she couldn’t get out of her mind, we could write them on a piece of paper (me scribing of course) which I would put in an envelope and seal, then lock it up in my desk drawer and say, “I will take care of these worries this week, and you can just leave them here with me, and they can’t get out because we’ve locked them in.” Sometimes this worked much better than Prozac, which, by the way came on the market around 1987.

…I do not want to make this sound like I was brilliant strategist. Actually about half of what I tried really worked. Sometimes the kids just laughed at me or balked, and occasionally I really screwed up…

…By the 1990’s, many other people were beginning to work on the upper part of the spectrum, and I no longer felt so alone… Even though I tried to preserve the part of my practice in which I saw other kinds of patients, I was deluged with spectrum kids and adults, often seeing as many as 10 Asperger’s patients a day, giving many talks about it, and doing lots of school consultations. I literally dreamed about fragments of Asperger’s conversations and sessions almost every night for at least three or four years, trying unconsciously to metabolize what I was immersed in… It is amazing how encompassing the Asperger’s experience can become… I find it uncomfortable to be considered an expert or “the Guru” on a subject that I feel I still do not completely understand and have a many unanswered questions about…

…These empathic failures in our society bring me much resentment and even more sorrow. But parents of Asperger’s individuals have to live with inflictions of even deeper sorrows. I want to return now to talking about the profound, highly personal, and private sorrow of bearing a child on the autistic spectrum, and then being forced to grieve for all that means in the deepest recesses of parenthood. I said a few minutes ago that I am not sure we talk as much about this as we ought to in these meetings, and I want to take a few minutes now…

…For parents of Asperger’s children there is in some ways a different kind of cruel touch: that is, many of the Asperger’s toddlers and preschoolers appear at first truly gifted. Those with hyperlexia are reading by age 2 or 3. Others have prodigious memories for facts and numbers, while some have encyclopedic knowledge of insects, the solar system, or… for species after species of marine life. While the parents are investigating educational programs for the gifted, the realization slowly dawns that sociality and reciprocity are significantly deformed. The special interests and splinter skills, which carry forward into childhood and beyond, can become a cruel reminder of the fall from earlier parental pride and delight.

The trauma of having a young infant labeled with the diagnosis of severe autism has been referred to vividly as a kind of internal “shattering”—a metaphor for me much like the sudden dashing into pieces of a plate of glass.

I have spoken with some parents of children with Asperger’s who have voiced similar but less intense feelings. I do not know this for fact, but I believe the experience of dislocation for parents of children on the upper half of the spectrum is perhaps less shattering, and is quantitatively different from the internal reactions of those parents of children on the more severely afflicted half of the spectrum.

Because of the slower unfolding and the lesser degree of the neuropathology, the diagnosis of Asperger’s is usually made at least three years later than that of Early Infantile Autism. For the Asperger’s parents, the fantasy and the reality have had more time to commingle and become more stable and substantial. There is much more opportunity for mutuality and reciprocity between parents and the Asperger child. Metaphorically, the “shattering” with Asperger’s Syndrome is more like the breakage of safety glass in a windscreen. The whole stays together better, fewer pieces fly off, and not at the same time.

But most important, the re-combining of the fragments, the restoration and healing for the parents of children with Asperger’s, is in the slow and steady growth and development of the child, in the child’s courage and creativity, and in his or her relentless tropism towards health, and hard-fought efforts at
empathic connection. It is the child itself who can do a lot to help restore for the injured parents their sense of inner worth, self-esteem, and integrity as parents. And that is one reason why the stakes are so high for optimal early and continued intervention…

…Today, in a more self-disclosing way, I thought I would touch on several deeply felt issues related to my own immersion in the Asperger’s experience… I believe these observations have relevance to all the many disciplines who treat people with Asperger’s, such as OT, Speech Therapy, Psychology, and Social Work, not just Psychiatry.

1) In deference to Eric Ericson, I will call the first observation, Fatigue in the Therapist vs. Energy Conservation. To those professionals of all disciplines in the audience this morning, I must warn you how exhausting it is doing on-going and multiple therapies with individuals with Asperger’s of all ages year after year. The required activity level, the constant need for creative reframing, the repetition, the accompanying of children out of the office, the effort to keep an emotional connection over time, to name a few, are extremely grueling and draining.

2) My second observation I think I will call Countertransference Loneliness vs. Shifts in Fulfilment. The intense psychotherapy of Asperger’s youth and especially adults can take a different kind of toll on therapists than just physical exhaustion. I am talking about the personal hardship a Treater faces trying to consistently empathize with a group of people who are so different internally. As I said in the beginning of this talk, like so many mental health professionals, I was drawn to this field by the wish to connect and understand.

There is some intangible but powerful satisfaction that transpires when you can let someone know that you share and understand a difficult feeling or an aspect of inner reality. Therapist and patient often do this nonverbally, by a subtle facial expression, a caring elevation of an eyebrow, leaning slightly forward, or some other delicate gesture that completes a reciprocal exchange of shared inner experience. Sadly, these moments are rare in the psychotherapy of individuals with Asperger’s.

Another very gratifying part of therapy with neurotypicals occurs when, after a great deal of tactful and thoughtful effort on the therapist’s part, the patient experiences deeply emotional insights or self-revelations, and these presumably lead to internal change and adaptation. These also are very hard to harvest in Asperger’s, where most therapy is cognitive behavioral, and relies on patterning of external behaviors and actions. If you are the kind of therapist who searches for these moments of affective transcendency, it can be like panning for gold nuggets in a muddy Sacramento River.

So insight-oriented psychotherapy can be very lonely and empty. I have had colleagues who’ve tried to do therapy with AS adults. They experience a sensation of being cut off, of feeling unable to influence anything that really mattered, except maybe some suggestions about job searches and advising on social skills. I myself feel that intensive life skills coaching is incredible useful, but still, there are many adults and even older children with Asperger’s, with whom one can do satisfying humanistic-relational therapy. The satisfying shift for me away from loneliness, lies in trying to understand the different inner reality of the patient. For most of us therapists, this a right hemispheric, inferential experience. In a very odd way, I have come to learn to empathize with Asperger’s folks by partially shifting right hemispheric intuiting, to a mixture of more left hemispheric analytical process. Who is this person? What would he feel, if he could feel something like I am feeling? How can I package emotional insight into left hemispheric language, and still convey relational connection?

It often comes down to how to truly feel and convey affection and fondness for the patient. One must be able to maintain a warmth for the patient, when the interpersonal life he talks about seems so flat and monotonous and emotionally drab, while at the same time the patient’s expressed excitement lies in facts and rule-based activities and graphic, left-sided “brain teasers,” like computer games or mineralogy or quiz shows.

3) This leads to my third point, which I will call Ability to Absorb Anxiety. One extraordinarily important aspect of the Asperger’s population is their pervasive anxiety. The anxiety fuels their rigidity. In my thinking, anything that reduces anxiety, by definition, increases resilience and adaptation… You cannot truly understand a person’s Asperger’s profile until you really understand his Anxiety. This can be somewhat different for each person. I am not simply talking about recognizing that it is there. We all know the usual arenas where the anxiety gets played out: transitional anxiety, performance anxiety, social anxiety, anxiety at discrepancy or at violation of expectancy.

I am referring to a need to comprehend the inner dimensions and the substance of the anxiety. At its heart, it is often a nameless disorientation, a loss of balance, an absence of any basic sense of trust or goodness in the future unknown or in the yet-to-be-experienced. The resistance to change, like all perseverations, is, at its core, a security operation. Deep inside, transition and discrepancy threaten inner cohesion and sense of inner direction, the loss of up and down. For many with Asperger’s, there is no internal compass to rely on, to show you the way in the forest of a new event. This feeling is often walled off by a dense protective shell of oppositionalism. If you force the issue, say as a parent, the child feels a ferocious sense of betrayal: “Why can’t you protect me, why do you make it worse for me?” To the frightened Asperger’s child, at that moment, the mother cruelly defrauds that unspoken contract of unconditional love, by relentlessly pushing the child forward into the mundane demands of life. From the Asperger’s child’s perspective, he or she is being shoved down the dangerous gauntlet: go to school, go to bed, cut your nails, change your underwear, eat this roasted chicken, call up that classmate, just try on the new dress. In his neuro-untypical soul, for the AS person, change and novelty is a storm cloud threatening inner disruption and dislocation….

…One of the major consequences of this family of disorders is social rigidity, lack of flexibility, and difficulty with spontaneous adaptation. In fact, descriptively, I often think of this overlapping population of children with Tourette’s, OCD, Asperger’s and ADHD as having a disorder of mental rigidity. Perhaps one of their most significant vulnerabilities is their lack of resilience…

(Article continues on next page.)
In the last decade, our society has learned a great deal about resilience in normal children... However, we who deal with Asperger’s Syndrome and these related disorders, have a special responsibility to figure out how to increase resilience in neurologically rigid and socially disconnected children. This is a difficult task.

We already know many techniques, but there is still much to be learned. The workshops we will go forth to after this address will highlight many of these techniques...

...But teaching resiliency in this population is more than a personal, a family, or even an professional issue. At the end of the day, fostering resiliency in these children and adults is all about the larger community. We, who live and work with autistic spectrum disorders, need to convey to the general community the crucial importance of support, acceptance and accommodation in schools and in the workplace, where many individuals with Asperger’s are still not understood well enough... We need to be resilient as a culture in order to foster resilience. Sadly, we are simply not there yet...

...There is a Wall in front of our disabled sons and daughters in this country. Perhaps it is weakening a bit, but this Wall is nevertheless higher and wider than it should be, and more impenetrable than we in this room want it to be.

...We are doing better, and our patients are so much better off than they were ten years ago. Many of our Asperger’s adults have gone on to make significant contributions in the workplace, and we can be truly proud of them. We should take hope and courage from these impressive gains.

But too many individuals with Asperger’s Syndrome and their families still live in the shadow of that Berlin-like wall I alluded to—in a lonely, isolated, stale-mated life of unrealized potential and stultified pain.

Today, there are people with Asperger’s of all ages who call out to us silently, with a voice they cannot lift because of the nature of their disability. They call soundlessly, but no less poignantly.

I ask you to raise your voices for them, to make yourselves heard in our schools, our workplaces, medical centers, research labs, and legislatures, and especially in charitable giving.

All of us can join voice symbolically and in reality with those silent individuals with significant special needs... We can be there, and we can make a difference. Thank you.

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**Dandurand Award Nomination**

by Joanne Odato-Staeb

Please accept the following to nominate Mario Bonavita for the 2008 Matthew Dandurand Award for Exceptional Effort. Mario is an 18 year old young man, diagnosed with PDD-NOS, who resides in Agawam Massachusetts. He is a full time, 11th grade student at Agawam High School, and resides in Agawam with his parents and his dog, Bella. Mario is a delightful young man who has surpassed the challenges presented by his disability in order to inform, educate and advocate on behalf of himself and others diagnosed with an Autism Spectrum Disorder.

I first met Mario in May 2007, when I was asked to be a part of his IEP team as the Autism Consultant. Mario was a 9th grader, having just transitioned into the high school in the fall. At the time, he struggled with heightened anxiety, and depended on adults to help facilitate and manage his day. He was mainstreamed in many regular education classes, however was not always considered a true member of the class. Much of what Mario shared with me that first year was his desire to have others understand and accept him better. He had previously worked with another Autism Consultant in attempting to understand how having PDD challenged him, but wanted to be able to understand more and share this with others (both teachers and peers).

With support, Mario developed a PowerPoint presentation about autism and how it affected teenagers like him. At times, it was difficult for Mario to understand and accept the struggles that he experienced verses a typical, non-disabled peer (especially around friendships), but he never wavered in his enthusiasm and positive attitude about who he is and what he would do to help others understand.

With the support of his parents, myself, and several very dedicated educators, Mario has had numerous opportunities to share the information he and I put together, as well as modifying it based on the particular audience. Since his initial presentation to his classmates, Mario has gone on to present to: the Agawam School Committee, the School Assistive Technology Committee, Porter and Chester Institute Adult Education Program for Nursing Students, Westfield Infant Toddler Services (a program that had provided services to him as a child), and as part of the school-wide Diversity in Education day. Mario is beginning to provide some small side stories related to his presentation material, which was not possible when he initially started talking to groups. He also helped develop a bulletin board display during Autism Awareness Month.

As a result of these activities, Mario has less anxiety, and increased confidence, self-understanding, independence, and friendships. Witnessing the personal changes in Mario, and hearing his presentations, has been “life-changing” for many of his peers, teachers, and providers. Mario’s presentation gave one student insight into a relative with ASD whom he had never previously understood.

Mario would like to continue to explore his interests in weather and music broadcasting, in addition to continuing to educate and inform others about autism, helping others to truly accept him and others diagnosed with ASD. He plans to present his Powerpoint to the high school Diversity Leadership group, Westfield Family Support Group, and the Agawam PAC. Part of his dream is also to meet other self-advocates (his idol being Dr. Stephen Shore).*

It is without reservation that I nominate Mario Bonavita for the Matthew Dandurand Award.

* Editor’s note: Of course, this dream came true at the recent Dandurand lecture—see page two of this journal!

You will find nomination forms for next year’s award at www.aane.org.
Executive Function Disorder in Children with Asperger Syndrome
What Is It, What Does It Mean for Kids, and What Can Be Done?
by Bonnie Glickman, M.Ed., NCC

Executive function is the ability to plan, organize and manage complex tasks. Executive function allows us to develop and apply problem-solving skills as circumstances call for them. We need executive function skills to deal with the stream of decision points we encounter throughout every day. Martha Denckla of the Kennedy Krieger Institute coined the term “ISIS (Initiate, Shift, Inhibit and Sustain to plan, organize and develop strategies or rules)” to describe these skills. Executive function skills tell us when and how to start or delay reactions to our environment, and to shift and/or sustain attention in order to prioritize our reactions.

Weak executive function skills (Executive Function Disorder, or EFD) can affect people of any degree of intelligence and capability. That being said, EFD is significantly more common in children with Asperger Syndrome (AS) as compared to neurotypical children (Attwood, 2006).

Symptoms of EFD frequently go undiagnosed or misdiagnosed, especially in early childhood. Once children reach middle or high school, organizational problems often become apparent. There are many good tools to help you determine if EFD is a problem for your child. You can find on the Web a survey that Leslie E. Packer has devised: www.schoolbehavior.com/organizational_problems_survey.htm or you can begin with the following list. Does your child:

- Have difficulty keeping track of possessions (books, notebooks, teacher’s notes, calculators, cell phone, lunch money)?
- Lose track of time and schedule?
- Start homework but not complete it, or not turn it in when it is due?
- Have a system of notebooks, binders, and class notes—but not use it?
- Have difficulties with working memory—the ability to hold information in one’s mind while processing and manipulating it (Barkley, 2005)?
- Feel challenged when attempting to organize information and relate it to previously acquired knowledge?
- Struggle with transitions (going from one class to another, one activity to the next, getting dressed, getting up in the morning)?
- Have a one track mind?
- Seem to be the last to know what’s going on?
- Fail to seek help if on the wrong track?
- Not know how to use an ‘inner conversation’ to solve problems (Attwood, 2006)?

What does it mean for kids?
Russell Barkley notes that executive functions are “critical to playing, organizing and carrying out complex human behavior over long periods of time.” Many children with AS have increased difficulties in everyday life due to low executive functioning (Lester, 2006). They may have:

- Slower processing speed
- Confusion when choosing from multiple options.
- Difficulty with reciprocal behavior.
- Difficulty generalizing information from one situation to the next.
- Black and white thinking that limits their ability to see subtlety or degree.
- Lack of a systematic approach to keeping order in their daily lives.

These factors increase their anxiety when dealing with change. Without closure, they often cannot achieve peace of mind and this can result in overload, meltdowns, and shutdowns.

What can be done?
People with EFD are often misperceived as lazy, unmotivated, stubborn or uncooperative. Usually, nothing could be further from the truth. They are working as hard as they can to keep pace with the demands in their lives.

According to a local expert on EFD, Sarah Ward, M.S.,CCC-SLP, of Lincoln, Massachusetts, one of the biggest complaints about children with EFD is, “They did it yesterday, why can’t they do it today?” For such children, however, the organizing pattern is not established in one pass; pathways must be developed through repeated practice. An important method of helping these kids is by teaching processing skills. Ward believes that this can be done most effectively through:

1. Segmentation: Teaching (not telling) students how to break down a task into smaller, manageable parts.
3. Mental picturing: Teaching students to think through a situation in order to envision how a goal can be accomplished.
4. Using visuals as a reinforcement.

Ward gives an example that uses these four techniques. A child was asked to set the table for dinner. She got stuck and overwhelmed in her attempts to do the task.

1. The child was helped to break down the task to a manageable level, in this case putting out four plates.
2. Once this was accomplished, the use of declarative language helped determine the next step. Rather than saying, “Okay, now put out the forks and knives” (imperative), the statement Ward made was, “Great, the plates are out. Now we’ll need something to eat the food with” (declarative).
3. In this one brief statement, the child was given specific positive feedback for what she had done (“Great, the plates are out” as opposed to the generic “Good job”), and was asked to assess the situation and figure out what came next.
4. Ward often uses photos or drawings to reinforce the concept being taught. In this case she used a photo of a correctly set table. It “conjured up the whole” and showed what it would look like if the table were set properly. Ward even Googled Hamlet to show whatever images there were to help a student write an essay about the character!
These concepts work equally well in school situations. As teachers we often say something like, “Take out your ruler and calculator and get ready for math.” Ward suggests that a better way to help students develop skills that will generalize to future situations is to say, “We’re going to do graphing now. How would your desk look? What is involved in graphing?” This teaches the student to become more self-directed by encouraging the development of self-talk, which Ward calls “notes to self.” The development of this kind of self-monitoring is essential to effective, independent thinking and functioning.

Another crucial concept children need to learn, Ward says, is the “sweep and passage of time.” She explains that we teach kids to read the clock, but this has little to do with monitoring the passage of time. Ward uses a wall clock with a glass cover and actually draws on its surface with erasable markers to block off the amount of time that will be allowed for a task. In Ward’s estimation this concrete visual “pie shape” method of demonstrating the passage of time gives a sense of control and improves motivation, because “They can see they are succeeding.”

Lynn Meltzer, Ph.D., uses a tool she calls Strategy Reflections Cards. These are index cards that students use to focus on the steps necessary to accomplish important tasks. The directives on the cards are created by answering leading questions such as, “Do you remember a time when you had trouble with a similar task? What did you do in order to be successful at this task?” Students then write out the strategies that work best for them on a card that can be laminated. When they undertake a task, such as studying for a test, they check the strategies that they have used successfully to study for tests. The card might say: 1. Flash cards; 2. Acronyms; 3. Two-column notes; 4. Mapping/webbing; 5. Discussing with a parent/friend.

Instead of the general checklists that work for many students, Meltzer notes that students with EFD need to make personalized checklists. Personally developed checklists help these students become aware of and search for patterns, identify their most common errors, and develop strategies that work in each content area. Below is Meltzer’s example of a math checklist:

- Read Directions.
- Reduce Fractions.
- Label Answers.
- Ask “Does my answer make sense?”

Many students with EFD lose focus with the repetition needed in studying. Here’s a technique that I use in my practice. Students read notes or written passages into a recording device, then play it back while actively reading along with the written material. This multi-sensory input lessens the tedium, and helps make students more responsible for their own studying. It appeals to the child who likes to play teacher, and gives practice to kids who speak too quickly or slowly, too softly or loudly, or who are reluctant to read out loud in front of others.

Children with EFD need help creating sustainable systems. When helping a child take charge of her life by cleaning up her room, I have her take a “before” photo, as Sarah Ward suggests, then get a big box and take everything that is lying loose on any surface and put it in. When the room is decluttered, we brainstorm categories for everything in the room: clothes, toys, books, school supplies, computer and technology, sports equipment. The child decides on the best location for the items in each category. Then we make official labels for the chosen locations. (Use address labels; Post-It notes will disappear in a day!) Then, and only then, does the child empty the box, placing one item at a time in the correct location. We take an “after” photo, and display it for easy reference and inspiration. A scheduled once-a-week refresher keeps the room orderly.

Take a student’s special interests into account when creating activities to teach and reinforce skills. An older student of mine loved designer clothes and dreamed of working in the fashion industry. We discussed what it took for a designer to create clothes and talked about what skills she wanted to learn. She agreed to learn how to use a sewing machine. This allowed me to embed needed lessons on executive function into her sewing lessons. She learned prioritization, prediction, sequencing, visual-spatial skills, and fine motor skills. She created a routine for taking out materials and putting them away, kept track of time spent, monitored the money used for material and patterns, and created a simple, but stylish dress—a tangible reminder of success.

Deficits in executive function skills render daily life, in school and out, confusing, exhausting, and at times humiliating. The common result of any good technique used to help kids develop executive function skills is the experience of control, success and mastery. Practical, simple, and inexpensive exercises, such as those described above, help our children practice and learn these necessary skills.

Bonnie Glickman is an independent educational consultant who specializes in working with children and adults with AS. She has been a special education classroom teacher, guidance counselor, and school founder. She works with clients, their families, and schools in Massachusetts and Rhode Island. For more information, please see www.bonnieglickman.com.

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For more information on Sarah Ward, please see www.executivefunctiontherapy.com, and the ad on page 21 of this journal.
Who will be the most successful in school and life: students with high academic achievement—or students with good social skills? Ever since Daniel Goleman’s work on Emotional Intelligence hit the popular press, we have increasingly come to realize the critical importance in our society of good social skills. If we are parents of children with Asperger Syndrome (AS), we know that the acquisition of social skills does not come easy—that it takes instruction and practice. We quickly learn that our children have a social skills deficit and need social skills training—but what exactly does this mean? What is taught in a social skills groups anyway? And should children learn social skills during the school day or outside of school? What qualifications should group leaders have? How do you decide which class will be right for your child?

Finding a Group

Since AS is becoming better known and understood, many schools are already providing some form of social skills training for their students with AS and closely related conditions—or even for socially challenged children who may not currently have a formal AS diagnosis. A student may work one-on-one with an adult professional, or be part of a “lunch bunch” or other small group. These groups may be led by a school speech therapist, psychologist, social worker, special education teacher, or guidance counselor, who may or may not have received specialized training in Asperger Syndrome and related Autism Spectrum Disorders. Groups may follow a curriculum with specific goals and lessons, or simply provide casual opportunities for students to socialize under adult supervision. Although the emphasis in this article is on community social skills groups, AANE strongly supports educational teams (parents plus educators) using every opportunity to teach children age-appropriate social skills at school, to train teachers and aides to provide coaching children apply those skills in real life situations throughout the school day, and to increase children’s social opportunities. For example, schools can provide an aide or other appropriate support so that a student can participate comfortably in an extra-curricular activity.

However, social skills are complex, and take time to master. Children and teens also need to be able to generalize their new skills—that is, to apply the skills in real life situations, not just in the speech therapy room. Given the demands of a typical school schedule, many professionals recommend that students also participate in after-school or weekend community social skills groups, to supplement the work being done in school. These groups provide opportunities for additional practice, and increase the chance of true mastery and generalization of skills.

Since this is such a new field, there are not many places where social skills are being taught outside of school. AANE maintains a list of community social skills groups on our website, under the “Articles and Resources” tab. If you don’t find a group on the list in your area, you could start by asking your community mental health facility about social skills groups. Other resources are area human services agencies as well as non-profits such as Easter Seals. Joining a parent support group—including both the online and face-to-face groups AANE offers—is another good way to locate a group, and to find out what other parents in your community do to help their children learn about and practice social skills.

Group Composition

In selecting a group, keep in mind that there needs to be time both for the formal teaching of skills, and for the informal practice of those newly acquired skills, and that this all needs to be done in an accepting environment. Our students need to feel safe to make mistakes, and to feel that they are accepted for who they are.

Some professionals advocate including typically developing peers (neurotypical or “NT” students—those who do not have AS) along with the socially challenged students with AS. However, many experts in the field—including AANE board member Elsa Abele—caution that students with AS benefit most from being in a group with children of similar cognitive and social abilities. Socially challenged students need to learn and practice specific social skills at much more length than neurotypical children; this repetition can be boring for the NTs, who don’t need this practice. Although one might think that NTs would be good role models for students with AS, children with AS do not learn and master social skills effectively just by imitating role models. Instead, they need explicit instruction in the building blocks of social interaction to learn the skills that come naturally to other, NT children.

Find out from the instructor how the social skills groups are formed. It is important for the cohesiveness and effectiveness of the group for the instructor to have individual intake interviews for each potential group member before the group composition is decided and the group begins to meet. The interview gives the teacher and the student a chance to meet and get to know each other before the first group meeting. One thing we know about our socially challenged children is that they don’t like surprises, or do well with transitions. The interviews help to make things a little clearer for the students; they know who the teacher is and where the group meetings will be held. The interview also gives the instructor an opportunity to put together a group of students who have similar interests and abilities. This is a very important ingredient for ensuring the success of the group. If the children don’t connect in some way then they will not want to come to group; if they do connect, they will be more motivated.

Curriculum

Many adults with AS, in addition to professionals working in the field, recommend that a curriculum be used for teaching skills that do not come naturally to the AS population. A successful program utilizes a step-by-step approach that includes explicitly defining and clearly describing particular skills, modeling, coaching, repetition, reinforcement, and many opportunities for practice. Inquire about the curriculum as part of your research into choosing a group for your child. There are some good curricula available, including works by Michelle Garcia Winner (see www.socialthinking.com), Jed Baker, the Skillstreaming series, and many books from AAPC. A good curriculum will provide a sequence of activities specifically designed...
to teach students all the steps of “the hierarchy of conversation,” as Elsa Abele calls it, or “social thinking” (as Michelle Garcia Winner calls it), and to practice each skill.

Of course, the instructor must also have a clear understanding of the group participants in order to convey the curriculum effectively. Certainly ask the instructor about his or her training and experience. Some instructors may have taken Elsa Abele’s two-day intensive training at AANE or elsewhere. Although many group leaders may be speech-language pathologists trained in social pragmatics, there is no single credential required in order to lead a successful social skills group. Some people seem naturally suited to working with students with AS. You can also ask for the names of one or more parents whose children have participated in groups with this provider, and who would be willing to serve as references by sharing their experiences and impressions.

Communication with Parents

A program that communicates frequently and directly with families is important. Children are most likely to be successful when families and social skills instructors work closely together and communicate regularly. Ask the instructor, facilitator or group leader how s/he communicates with families and whether s/he lets families know what they can do at home to practice skills and reinforce learning. This chance for home practice helps our students really integrate the new skills into their social repertoires. Find out if the instructor asks families what types of skills they would like their child to work on. It is also important for the group facilitator to know what families are thinking so there is less opportunity for miscommunication. Also ask for the names of other parents whose children have studied with the instructor and ask them about their experiences, including by what means, how often, and how well they feel the instructor communicates with parents.

Generalizing Skills to the Real World

Another feature to look for in a good program is to find out from the instructor if there are opportunities for generalization of skills into real world settings—special meetings that take place in a more natural setting out in your community, rather than in the usual office or classroom setting. (This is also where an after-school program could differ from an in-school one.) Research shows that having plans for maintenance and generalization of newly acquired skills is one of the keys to helping children integrate these skills firmly into their repertoire. So ask if all the lessons are in an office setting, or if there are plans for trips and activities outside of the office. Practicing ordering food from a waitress at a restaurant in the office is very different from actually doing it in a real restaurant! This also gives the group a chance to have some shared experiences. Typically developing children often reflect on their shared experiences, and this develops a closeness that defines friendship. A skilled instructor will help the students in a group start to develop some ability to reflect in this way, and use these experiences as a jumping off point to learn about making and maintaining friendships.

Benefits of a Social Skills Group

In addition to learning skills that can help them throughout life, children participating in good social skills groups benefit immediately from being understood and accepted by a group of peers. Without this kind of experience children with AS, especially as they enter the teen years, can become anxious and depressed due to their social isolation. Belonging to a compatible group is a great solace and good preventive mental health. Some children may develop friendships with the other members of the group that extend beyond the meetings.

Along with social skills, your child may also learn some daily living skills (such as making a snack or taking a bus) that are an important part of growing up, and that many children with AS miss because of their lack of awareness, or because parents may be too exhausted or discouraged to teach those skills.

When your child is learning skills with an instructor who understands the AS population, and has a group of peers with whom to practice, the burden of trying to teach your child everything will be lessened. You can then feel calmer about your child’s development—and having calmer parents is always a good thing! Instead of having to be your child’s social skills teacher and social coach, perhaps you will be able to just be a parent—to relax a little, and to spend more time just enjoying life with your child.

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Helping Teens Who Struggle with Writing

My daughter with AS has always struggled with written expression. Here’s a few things that have been helpful, although none have been a magic bullet:

1. **Super Sentences**: She is encouraged to take a sentence and add adjectives and phrases to expand the sentence. For example, if she writes “I went to the beach. It was hot,” she’ll be encouraged to expand it to something like “I went to a sandy ocean beach. It was so hot I thought my skin would melt.”

2. **Using a computer**: She does all her writing on computer now. It’s not that the physical act of writing is difficult, but it does seem that it requires using areas of her brain that interfere with thought. She uses a “jump drive” (flash drive) or emails documents to herself to get them back and forth to school.

3. **Dictating to parents**: Hard to resist the temptation to edit! I think having a parent at her side helps contain her anxiety. Showing real interest in the topic gets the creative juices going. Sometimes I’ll feign ignorance of something just so I can ask her relevant questions.

4. **Being able to choose what to write about**, especially things she feels strongly about. For example, writing a letter to the Superintendent about snow days. Argument comes more easily to her than something she sees as pointless. “Why should I care about this?” is a typical reaction to being asked to write an essay or book report. I really think it’s a struggle to get her mind around something that seems pointless to her.

5. **Writing fiction**, particularly “fan fics” which are stories about anime characters. (See www.fanfic.net.)

Some things that did not help:

1. **Graphic organizers** just made her hate writing. I think she would have done better just to be encouraged to write.

2. **Dictation software** she found very frustrating.

She just spent about a week writing a two-page paper (she’s a high school freshman), so her writing production is still much less than it should be. But she did this paper with no tears or tantrums, and was proud of the result, so she’s made tremendous progress.

Annie

I have worked with high school students with severe writing problems. In addition to other good suggestions here, I recommend patience, patience & more patience. Students so often want writing to be easy—and to have it easy right now! Praise the student who tries, who sticks with it, who turns in assignments on time...It’s often slow & frustrating, but keeping a child working, helping him or her to keep trying, all this really helps over time.

One child I worked with could only keep her mind fixed on a subject when she was either doodling or in some other way using up her anxious energy. (I encouraged her to walk-and-talk-and-dictate to me but she wouldn’t.) Some need to eat. In one case I broke down the assigned topic into questions, which I asked; the child typed out (or wrote out) the answers. One child was stuck on an exam question and nearly in tears in the resource room. We suggested he take a break to go visit the pet dog who had come to school with a teacher that day. He came back calm & relaxed & and went back to work. Anything to keep them moving forward & confident! Eventually they begin to believe they can do it. Good luck!  Barbara S. (parent and professional)

Two Different Worlds

My son Brian was born prematurely, weighing a mere 2 lbs., 13 oz. We were prepared for “something”, but we didn’t know what it was going to be. When he was four years old, Brian was diagnosed with PDD-NOS. Currently, he is in first grade in an integrated setting. Our life is not what you would consider to be “typical.” While others are at soccer practice, Brian is in therapy.

All I ever wanted was for Brian to fit in with his classmates. I almost made it a full time job trying to find him a playdate—*any* playdate—but no one would return my phone calls or emails. I don’t think that Brian understood why no one wanted to come over. He knows he is different, but doesn’t quite understand how. Every day, as he gets off the bus, he asks me, “Mommy, who is coming over today?” It hits me in the gut when I tell him, “No one, sweetheart.”

We wanted his school life to be normal, and for our family to fit in with the community. I longed for the day when we could just be the everyday people next door. However, that day never came. I was at every PTO meeting and served on every committee—but it didn’t help. Within the past several months I have come to the realization that there are two worlds out there. There is the typical world and then there is the special education world. For a long time I didn’t realize this—or I didn’t want to see it—but our family was very quietly being shoved out of sight. I began to realize and accept that we were never going to fit in. This is something that slowly seeps into your mind when you aren’t looking—and it hurts, terribly.

I think you can describe the two worlds as two big bubbles. The bubbles try to mesh and meet—but for us, as for many families, this did not happen. It took me a long time to be able to make this enormous transition, but I think we made it gracefully. All we ever wanted to do was be normal, but you know what? We ARE normal—for us. We are normal for our wonderful SPED community, and I am extremely proud to be a member. It is a very, very scary time when you realize that you have to make some sort of change, but don’t know how or where. For me, the time came to let go, to trust my instincts and let nature take over. So far, it’s ok. I have learned many hard rules and lessons over the last few years, but I manage to push my way forward. I have to stay on this journey because I have a very special boy who needs acceptance and a healthy life. Life is not what most people would call ordinary, but it is ordinary for us. We are a special needs family. We are on a new path, with a new found community, and this will be the path that we will all stay on.

Alison Eskenas
It’s Time to Accept Us (For Who We Are)
by Danny Sandberg

I have always had a strong interest in and understanding of sound, and really enjoy composing music notes and lyrics. As I thought about writing this article, I also spent time thinking about composing a song that would reflect my thoughts about the process or journey that I have taken to get to where I am at with my understanding of myself and my desire to help others. I will share some of the song lyrics later.

When I first thought about educating others about Asperger Syndrome (AS), I did not know that I would gain so much knowledge about myself. I was frustrated and in a high state of Anxiety because the educational staff around me did not know how to help me to access my strengths for learning. Their approach to me was to enforce compliance and conformity to what they believed I “should” be doing, learning, behaving, and thinking, based on their experience with neurotypical students. “Thinking outside the box” or attempting to understand things from my point of view were not in their repertoire—even though I was enrolled in a school that was supposed to access “creative and individualized approaches” to student learning. HA! Somehow I guess that didn’t really apply to me. Because of this emotionally damaging experience, I started to doubt my skills and abilities. My solution was to start with teaching them (and myself) more about AS. After all, this is part of who I am, and I wanted to be proud of that.

I started working with a private autism consultant, Joanne Odato-Staeb. We identified that my best mode of learning was using visual supports, so we decided to start with developing a PowerPoint presentation that I could show to teachers and possibly peers at my school. Joanne provided me with material to read, and encouraged me to search the internet for ideas, stories, facts/myths and bios of people with AS. I began identifying similar struggles, challenges, experiences and wonderful skills, which I shared with others. Joanne, along with my parents, helped me to begin to understand how my thinking and perspective might be different from others’ (especially neurotypicals’) and that it wasn’t a bad thing, just different. I also began (with support) to understand that others might not think of something in the same way that I do.

Thankfully, I left the school that I was in at the time. They did not really support my wanting to educate the teachers and peers; they believed they were already “educated.” They never were able to find the time (in the school year), for me to share my PowerPoint presentation with anyone. (Fortunately, Joanne was able to give me my first “start” as a presenter during a parent training workshop for Community Resources for People with Autism.) By the time that I left, my confidence, self-worth, and skills were basically in the toilet, and starting another school program was quite overwhelming. However, my parents found a wonderful new school, Pioneer Valley Performing Arts Charter School (PVPA), which would lend itself completely to my music interests while providing flexibility for me to develop trust with the teaching personnel (although this will always be a struggle for me).

When starting the new school, I also wanted to start right away with educating the teachers and students about Autism Spectrum Disorders, in particular AS. Joanne helped me to further develop my presentation (which I understand will continue to change and grow as I do). During the first year at PVPA, I did five presentations! One of my slides is about my future goals. I am interested in being a music producer, but also to continue educating people about AS.

I believe that when I share my PowerPoint presentation with others, not only does it educate, but it can also show others with ASD that they too can stand up and be heard by others. I feel that my work is empowering me to become more confident in letting people know what I need, or to clarify miscommunications better. Don’t get it wrong, I haven’t mastered it yet, but I do believe that it’s time for others to accept us for who we are. I feel that if I can stand up and be heard, maybe I can open the door and encourage others to do it for themselves as well. At the end of one of my presentations a young lady came up and shared that everything that I said was exactly the same as what she has been experiencing her whole life! She said she knew something was different about how she was thinking, but didn’t know “it” had a name—it was AS! She wanted to know what to do next, and who should she talk with. I told her that other than her family, she should see a neuropsychologist or at least her doctor to see if AS is what she has. She was very happy to know someone else shared her experiences, and she thought what I was doing was wonderful. It is wonderful to know that I can help others understand themselves better. I feel that I will educate people whether they think I’m cool or not.

When reading about people in history thought to have an ASD, Albert Einstein comes to mind. Einstein had some problems making friends, would not comb his hair and was thought of as different and slow. Most people look at Albert Einstein now and say “what a genius,” but I have a different perspective. I see an inspiration, an example of the opportunities available and the achievements possible for people with ASD. By educating and hopefully inspiring others, I hope to open the door for greater acceptance and appreciation of many people with ASD, including myself. I believe I have a gift to educate through my presentations. I understand that not all people with AS can do this, but for those of us that can, we must continue to advocate for ourselves and open the doors for greater understanding and acceptance. I am available to present to colleges, businesses, schools and parents in order to create a different perspective of ASD: the gifts, and celebrations of what is possible. We all have value and need to share our strengths with others.

It’s Time to Accept Us (For Who We Are)

Why is it, in conversations
When people my own age
Are talking ’bout somethin’ cool
I try to join in but soon feel overruled
It makes me feel alone
I don’t give up
Never will
It’s too important not too © Daniel Sandberg

To chat, or to schedule a training/speaking engagement, email the author at danielsandberg1011@gmail.com.
Differences
by Marc Vogel

Everyone is different. Differences come in all shapes and sizes, but some people are more different than others. Sometimes these differences come in the form of disabilities that can affect your whole life, like blindness, hardness of hearing, or dyslexia. Some differences come in the form of medical problems that can also affect your life in some way, which come in a wide range from minor ones like asthma, to deformities that can make your life very different from average people’s lives. Also, some people’s brains function differently than others.

Sadly, many people choose not to make friends with some people because they have a “problem.” They’re not problems, though. They’re simply differences. So we must learn to acknowledge the fact that even a person who has a “problem” can still be your friend if you let them, and that in the end, you will be happy you gave someone a friend.

When I first went to the K-3 Kindergarten in Stratton Elementary School, it wasn’t long before I realized I was different. For example, it was December when I first went there, and I was celebrating my 5th birthday. I didn’t really like being dragged out of my pre-school so early. Luckily, I met a bunch of friends who I hope to reunite with when I get to Ottoson. I noticed that every one of them was different in some way.

My years in 1st, 2nd, 3rd, and 4th grade showed me that I was even more different than I thought. For example, I noticed that when I got REALLY angry, I unleashed my full fury, like that time when I missed a bookbinding thing at school with my dad. I don’t do that anymore, though. I also noticed that in 1st grade, I tried to be funny, like the time I went to Spanish class, bent over, and said, “Hey, why is the Spanish class upside down?” My second grade teacher ended those days. The last time I ever did any of that stuff was when I switched the desk names of two people whose desk names were coming loose. I never told about that until now. (Except maybe once.) Also, I noticed that people say I am really smart, but I didn’t know why, but that wasn’t so bad.

Anyway, once my doctor said I had Asperger Syndrome. What is that, you ask? Well, it’s not a bad thing, that’s for sure. It’s one of those different-brain things that I mentioned earlier. I think that they told me that this means I excel in some things but am lacking in some social skills, like tact. But I noticed that I have a lot of friends (nearly all the fifth grade) and I decided that I wouldn’t change myself even if I could. It just goes to show that just because you’re different doesn’t mean you’re not a good person.

P.S. This sounds like something a psychologist would say, doesn’t it?

Grandparents’ Corner

We too are grandparents raising our grandson with AS, who just turned 18. There have been numerous times when we were certain that we’d just crumble under the stress associated with the many obstacles we’ve encountered on our journey. We dealt with a school system that didn’t understand his needs, or didn’t care about them, so we needed to schedule a hearing with the Dept of Education. The ruling was in our grandson’s favor, so we began the search for an appropriate school. It took us five years to find a placement that worked for him. When he wasn’t in school, I tried to homeschool him with marginal success. I think the most difficult part of raising any teenager is the extraordinary amount of energy needed to guide them successfully into adulthood. Our children are driven by anxiety and sensory issues that require more patience, energy and accommodation by the adults in the home than the “average” teen. Our grandson often becomes stuck on a plan and it’s difficult to dissuade him. Family members have been less supportive than we’d hoped, so we’ve used non-family to help us with some of our grandson’s activities that are beyond our physical and/or emotional ability. When he was a youngster, I hired graduate students from BU to spend several hours a week entertaining him, taking him to the zoo, museums, bowling, etc. During his teen years, we enlisted the help of various agencies to provide information and support to help ease the demands placed on us. I can empathize with your feelings of exhaustion.

The good news is that your grandson is getting to the age when he’ll be able to learn to drive and, hopefully, get himself to the activities he’s interested in. The bad news is that you’ll worry when he uses the car. Are his interests shared with any friends or acquaintances whose parents could take turns with you driving the kids to the events? Alternately, would you feel comfortable teaching him to use public transportation? You’d need to figure out bus schedules for him, but with explicit instructions, he might be able to negotiate the trip by himself. Our grandson has just recently recognized that we don’t have the stamina to cater to his every wish, so he’s learned to compromise. It took a lot of time and patience to teach him that we would do as much as we could, but when we say “energy depleted,” we expect him to respect our limits and rely on a fall-back plan. I think that what we lack in energy, we make up for in wisdom and patience. Your grandson is lucky to have you as his caregivers.

Gail

New Grandparents’ Group Forming

AANE is offering a new 6 week group for grandparents of children with Asperger Syndrome (or such closely related disorders as HFA, PDD-NOS, or NLD). Some group members may be working on ways to help adult children raise the grandchild, while others may themselves be raising a grandchild in place of the parents. Meetings will take place in AANE’s Watertown office. The cost for all 6 sessions is $150 for AANE members and $185 for non-members (includes cost of a new membership). For more information, or to register, please contact Grace Myhill, LICSW, 617-504-3116 or gmyhill@gmail.com.
Adventurous Connections in Plymouth County, MA
by Catherine Mayes, Coordinator
AANE Plymouth County Teen Service
(617) 999-7639 or catherine.mayes@aane.org

Starting in 2008, through the generosity of the Edwin Phillips Foundation, Plymouth County families with teens with AS have been able to participate in programs in Norwell, Marshfield and Plymouth, Massachusetts. For example:

Teen artists learned more about the art of manga with instructor Bettina Kurkoski, creator and publisher of My Cat Loki. AANE’s “Manga Madness” workshop series was held at and co-hosted by the ARC of Greater Plymouth. “Homework and Writing,” presented by Jean Stern and Brenda Dater was held at the Norwell Public Library and was well attended by parents and educators. Dr. Joseph Shrand and Mr. James Quine, unraveled the mystery of “Theory of Mind in Theory and Practice” at Ventress Memorial Library, Marshfield, Massachusetts. Dr. Shrand drew on his over twenty years of experience as a child psychiatrist. He used humor in the form of New Yorker and Far Side cartoons to help attendees better grasp theory of mind. Mr. Quine, a middle school teacher, explained how theory of mind plays out in the classroom. A high school student with AS completed the program by he graciously answering questions about how he gained greater understanding of how theory of mind affected his ability to develop friendships, succeed at school, and date. “Rules of Attraction: Sexuality Issues and Concerns for Teens in High School,” was led by certified sexuality educator Sally Fogel, M.Ed. at the Marshfield Recreation Center. Sally worked with a group of over a dozen teens, while Catherine Mayes led a lively parent discussion and networking group. “March Madness,” held at the Plymouth Library, gave families an opportunity to review their IEPs with a Massachusetts Advocates for Children’s Autism Project Advocate in preparation for upcoming meetings with schools.

AANE Presents
Executive Functioning Strategies
Sarah Ward, M.S., CCC-SLP
May 26, 6:30-8:30pm
Ventress Library in Marshfield, MA

Sarah Ward has over 14 years of experience working with students with executive function deficits, and is a top local authority on this topic. (See article on page 7 of this Journal.)

Pre-registration is required.
Please see the upcoming events section of www.aane.org, or contact Catherine Mayes at (617) 999-7639 or catherine.mayes@aane.org

Made possible through the generosity of the Edwin Phillips Foundation

Above: Manga by Liz Young, student of Bettina Kurkowski.
Below: Covers of two of Bettina’s books.
For more information, please see www.dreamworldstudio.net.
At AANE’s “Seeing with a Different Eye” exhibit in fall of 2007, AANE member Bob Washburn saw two of paintings by Wanda Metcalf. Shortly afterwards, he commissioned the painting shown above. Bob lived in this house from 1945-1954, from the time he was two years old until he was ten, at which point the family moved to Lexington, MA. For Bob, this painting of his former home brings back wonderful childhood memories. (Contact Wanda through AANE.) Beautiful catalogs of the 2007 “Seeing with a Different Eye” exhibit are available through the AANE web site. Our second exhibit will have its premiere at the Asperger Connections 2009 conference on October 2nd at John Hancock Hall. Who knows what other wonderful things will result from this second exhibit?
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New Groups Forming

AANE is offering new groups for:

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♦ People Divorced from/Co-parenting with an Individual with Asperger Syndrome
♦ Individuals with Asperger Syndrome who are in relationships with someone who does not have AS

Each group will hold 6 once-a-week sessions to provide mutual support and increased understanding about the effects of Asperger Syndrome on relationships. We will explore coping strategies, including ways to improve communication in couple relationships. The start date will be determined when enough people have signed up to begin a new group.

Groups are led by social workers with knowledge of and experience with adults and couples affected by Asperger Syndrome. Group size will be between 5 and 10 participants. Meetings will take place in AANE’s Watertown office. The cost for all 6 sessions is $150 for AANE members and $185 for non-members (includes cost of a new membership). For more information, please contact Grace Myhill, LICSW, at 617-504-3116 or gmyhill@gmail.com.

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AANE ha verificado que los adolescentes y los adultos jóvenes con Síndrome de Asperger (SA) tienen significativamente más encuentros con los servicios de emergencia, en especial con la policía. Los adolescentes suelen caminar mucho, principalmente de noche y son con frecuencia interrogados por los oficiales de policía. Algunos adolescentes pueden no darse cuenta de su propia apariencia y verse sospechosos. Otros recogen cosas y son interrogados. Hay quienes se meten en problemas con la ley cuando usan alcohol o drogas o las compran para “amigos” sin prever las consecuencias. A veces, un niño tiene una crisis en público o comete un exabrupto. Ocasionalmente, puede huir del hogar o vagar sin tomar conciencia y sin pensar al respecto.

Un encuentro con un agente o personal de seguridad es una experiencia generadora de ansiedad para la mayoría de nosotros; lo es aún más para individuos con SA. La tarjeta de información –que puede obtener en la página web de AANE, www.aane.org– ofrecerá una guía para ayudar a las personas con SA a interactuar más efectivamente con los servicios de emergencia, a mantenerse seguros y paliar una situación tensa.

To: A Law Enforcement Officer or other First Responder
I have a diagnosis of Asperger Syndrome.

My Name: _____________________________________________________________
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In case of emergency, or to assist both you and me in communicating and in resolving this situation, please contact one of the following people:
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Cruzando fronteras con el Síndrome de Asperger (S.A.)
por Charlie Remy

Fui a Nicaragua en enero con un grupo de compañeros de la Facultad de Biblioteconomía de Simmons College (estoy haciendo una maestría allí). El propósito de este viaje fue hacer un voluntariado en bibliotecas nicaragüenses - particularmente la Biblioteca Móvil de San Juan del Sur. Decidí quedarme por una semana más para viajar a otras ciudades y conocer mejor Nicaragua. Fue un viaje muy bueno - pude hablar español como quise, aprender de la cultura e historia de este interesante país centroamericano, conocer a un autor famoso (Sergio Ramírez), y ayudar a promover bibliotecas y lectura a cientos de niños nicaragüenses.

Durante mi última noche en Managua, me reúni con Jorge, un auto-diagnosticado Aspie de 24 años. Lo conoci a través de un foro para adultos con S.A. hace unos meses. Este foro ha sido una herramienta genial para mí - me ha permitido comunicarme con gente Asperger por todo el mundo hispano (Argentina, Colombia, España, etc.). Mi fluidez en el idioma me ha dado muchas oportunidades de socializar con monolingües nativohablantes de español con quienes no podrían compartir experiencias si no supiera el idioma.

Jorge estudia química en la Universidad Nacional Autónoma de Nicaragua (UNAM) y ha pasado mucho tiempo tratando de aprender más sobre sí mismo. Sobre su personalidad encontró algo sobre el sindrome cuando estaba navegando por la red un día. El problema es que en Nicaragua la mayoría de profesionales de medicina están ligados a paradigmas anticuados que han definido el significado de autismo. Cuando conocen a Jorge, le dicen que no puede ser autista porque habla de una manera normal y es estudiante universitario. Esta actitud combinada con la falta de recursos disponibles para adultos con S.A. en Nicaragua es muy frustrante para él.

Jorge viene de una familia de cinco hijos; viven en las afueras de Managua. Su padre trabaja en ventas y su madre es ama de casa. Es interesante que él no haya compartido nada sobre S.A. con su familia. Prefiere mantenerlo privado aunque piensa que ellos ya se han dado cuenta que no es “normal” de una manera neurotípica.

Una de las cosas más importantes de Asperger es que ninguno de nosotros somos exactamente iguales. Si hay similitudes y características que tenemos en común pero no hay ningún Aspie prototípico. Jorge y yo hemos tenemos problemas con las relaciones románticas. Él ha tratado de salir con chicas en el pasado y no tuvo mucho éxito mientras que yo no entiendo su ayamado esta punto. El es hiperensensible a los sonidos como yo. Pasa hora tras hora en su biblioteca universitaria absorbando información como una esponja.

A Jorge le interesó mucho aprender de AANE y los tipos de actividades que ofrece para adultos con S.A. Le conté sobre la conferencia anual, la oportunidad que tuve para conocer a Tony Attwood, el taller de relaciones románticas, y otros eventos donde he participado. Después de aprender de la falta de apoyo y consciencia sobre S.A. en Nicaragua, me sentí muy afortunado por tener un recurso tan valioso como AANE tan cerca de mí en Boston. No lo puedo dar por sentado ahora porque conozco a gente en el extranjero a la que le encantaría tener acceso a una comunidad tan cariñosa.

Le agradezco a Jorge haber viajado una hora y media por transporte público para poder conocerme en el hotel. Fue un final genial para un viaje inolvidable. Espero que éste sea el primero de muchos encuentros que tengo con Asperger’s en el mundo hispano. Experiencias como ésta amplían mis horizontes y me hacen darme cuenta de que no soy el único para el que puede ser un mundo cruel y frustrante para nosotros quienes no somos neurotípicos.

[In January I went to Nicaragua with a group of classmates from Simmons College Graduate School of Library and Information Science, where I’m working on my master’s degree. The purpose of the trip was to volunteer in Nicaraguan libraries, particularly the Biblioteca Móvil project in San Juan del Sur. I decided to stay an extra week to travel to other cities and get to know Nicaraguan better. It was a great trip! I was able to speak Spanish as much as I wanted, learn about this interesting Central American country’s history and culture, meet a famous author (Sergio Ramírez) and help promote libraries and reading to hundreds of Nicaraguan children. On my last night in Managua, I got together with Jorge, a 24-year-old self-diagnosed Aspie. I met him through a Spanish language listserv for adults with AS a few months back. This listserv has been an amazing tool for me. It has allowed me to connect with many people with AS across the Spanish-speaking world (Argentina, Colombia, Spain, etc.). My fluency in the language has opened up opportunities to communicate with monolingual native speakers of Spanish who I would otherwise not be able to share experiences with. Jorge studies chemistry at La Universidad Nacional Autónoma de Nicaragua (UNAM) and has spent a lot of time trying to learn more about AS. He happened to come across it while looking on the internet one day. The problem is that in Nicaragua most medical professionals are stuck in the old paradigms that have traditionally defined autism. When they meet Jorge, they say that he cannot be autistic because he talks normally and attends college. This attitude, along with the lack of resources available for adults with AS in Nicaragua, are very frustrating for him. Jorge comes from a family of five children; they live on the outskirts of Managua. His father works in sales and his mother is a homemaker. Interestingly, he has not shared anything about AS with his family. He prefers to keep it to himself although he thinks that they realize that he is not quite neurotypical or “normal.” One of thing important things to understand about people with AS is that none of us are exactly alike. There are indeed similarities and characteristics that we might have in common, but there is no prototypical Aspie. Both Jorge and I struggle with romantic relationships. He has tried dating in the past and it never really went anywhere, while I haven’t even gotten to that point yet. He is hypersensitive to sounds as I am. He spends hours and hours in his university library soaking up knowledge like a sponge. Jorge was very interested to learn about AANE and the types of activities that it offers for adults with AS. I told him about the annual adult conference, the opportunity that I had to meet Tony Attwood, the relationship workshop, and other events that I have participated in. After learning about the lack of support and awareness about AS in Nicaragua, I feel very fortunate to have such a valuable resource as AANE so close to me in Boston. I cannot take it for granted because I know people around the world who would love to have access to such a supportive community.

I appreciate Jorge having travelled an hour and a half on public transportation to visit me at the hotel. It was a great end to a wonderful trip. I hope that this is the first of many encounters that I have with Aspies in the Hispanic world. Experiences like this both broaden my horizons, and make me realize that I am not alone in what can often be a cruel and frustrating world for those of us who are not neurotypical.]
North Star Foundation is a nonprofit whose mission is to place assistance dogs with children who face challenges. To date we have helped over forty families meet the social, emotional and educational goals of their children on the autism spectrum, through the use of well-bred, well-trained dogs.

Our dogs play a different role than traditional assistance dogs. While most assistance dogs need to have a multitude of trained skills, such as turning on or off light switches, our dogs tend to face less technical tasks, such as comforting a child through a tantrum by offering a relaxed presence and focused attention. On the surface, a long, attentive “down/stay” seems easy, and not especially glamorous to train; however, the ability to stay calm in the face of a child’s loud emotional upset requires a dog that has a mellow, nonreactive temperament and a long history of understanding that children's tantrums are sound and fury that signify nothing. We select and socialize our dogs to safely and effectively intervene in the face of a child’s meltdown or anxiety.

We are committed to finding the optimal fit between child and dog, and then supporting this team as they grow together. The pups we select have a genetically heightened ability to read the social cues and establish strong communication with a child. North Star puppies are raised in puppy-raising homes, and have supervised contact with their designated children as early as possible. Traditional assistance dogs are placed with their partners when they are over two years old, but for a child with a developmental disability delayed placement could negatively affect bonding between the child and the dog. By two, a dog’s temperament is well established. If the dog has not had exposure during the early months to the child in question, or to the specific challenges s/he presents, the dog might react unpredictably. Children with autism or other developmental disabilities often display unusual behavior; sometimes they throw loud tantrums or fail to grant the appropriate body space that we unconsciously and consistently grant each other. Dogs depend greatly on nonverbal communication, and are apt to be uncomfortable with violation of personal space.

When we select a puppy to work with a child, we look for superior social skills and a large measure of intelligence and problem-solving ability. We then nurture these qualities. A concept called “intelligent disobedience” is especially valuable. If a blind person approaches an open manhole, it is desirable that the dog ignore the command to “Go forward,” and instead lie down in front of his/her partner. This quality of understanding needed to interpret their environment and protect his or her partner, is largely found in the dog’s genes, but must be nurtured. Our method of training North Star dogs is completely positive, and we reward a dog for thinking for itself. A pup afraid of physical correction can become too afraid to think for itself and disobey a command. For example, if a child suddenly takes off, you need a dog that will shadow him—even if the dog has been given the command to stay in the yard.

Supervision is essential to creating a successful placement. We must establish optimal behavioral patterns right from the start. Dogs take their cues about relationships from humans; training is just a concentrated form of communication about what behaviors we want to encourage or discourage. If a child with autism does not make it clear to a puppy that playful nips hurt, then the puppy will naturally nip more. It is important for the child’s caretakers to ensure that the relationship between child and puppy is consistently gentle and mutually enjoyable.

Above all, a child with autism should be fully integrated into his or her own family. Therefore, all of North Star’s placements are family-based, with every member given a special job to perform. The dog becomes a focus of attention, increasing both communication and fun for the whole family. Parental involvement is crucial and, although time-consuming, can be pleasant. Incorporating a well-bred and well-trained puppy or dog makes time spent working on a child’s social, emotional, and educational goals more focused and fun. Attention must be consistent and educated, but the parents I have come to know pay this type of attention to their children already! Parents get to love this dog as much as their children do, and enjoy the emotional support the dog gives them so freely. Job assignments are created to help the dog form individual bonds with every member of the immediate family. For example, jobs such as feeding will be given to the child with a challenge, but we also try to draw the rest of the siblings into walking or grooming the dog.

For a child with autism, spoken language can get in the way of successful communication. After an exhausting day struggling to communicate with humans in words, spending time interacting nonverbally with a dog is a welcome respite, and can greatly reduce the frequency of meltdowns. “Time out” can be a positive thing, when the dog is present to provide comfort. Children with autism often have great difficulty in generalizing learned speech to new situations and people, due to their overly selective attention and tendency to respond to a limited number of cues. An assistance dog can act as a bridge to help children generalize speech out into natural settings, both the home and the outside community. Adults can help the child rehearse stock responses to the fairly predictable questions people are likely to ask when they see a well-trained dog wearing a vest with a patch that reads “Please Ask to Pet Me.” People who may have shied away from starting a conversation with your child often relax and rise to the challenge when a dog is available to help structure the questions and comments.

However, perhaps the most important way North Star dogs help children is to increase their self-esteem and feelings of social and emotional competence—including empathy and theory of mind. Actively engaging a child in raising a puppy teaches responsibility, and also helps the child take another’s perspective. As dogs are much simpler to understand than people, they are far easier for children with autism to relate to. Most of the children become very solicitous of and attached to their dogs, and these relationships can become stepping-stones to more socially and emotionally complicated relationships with people.

Coaching clients frequently ask me whether they should disclose their disability to an employer. My answer is, “It depends.” The best approach is to develop a personalized plan based on the many factors that affect employment outcomes. These factors include an individual’s job skills, primary challenges, employment history and career.

Disclosure can benefit individuals who are currently employed as well as those who want to be. If your challenges are very noticeable or hard to manage during the work day, disclosing can be much more effective than simply hoping that your social and communication problems or organizational difficulties will go unnoticed.

Disclosing also compels an employer, under the Americans with Disabilities Act (ADA)\(^1\), to make reasonable accommodations for qualified employees. An accommodation is a modification or adjustment that allows a disabled individual to participate in the interviewing process or to perform the essential functions of his or her job. Examples of reasonable accommodations include providing written instructions, allowing the use of headphones to block office noise, a modified training program, flexible scheduling, etc.

On January 1, 2009 the Americans with Disabilities Amendments Act (ADAAA) went into effect. It changes the way that disability is defined, thereby greatly increasing the number of people who will now qualify as being disabled in the workplace. More significantly, it shifts the focus way from whether an employee is disabled or not, and places the emphasis on whether an employer meets its obligation to accommodate a disabled individual. This bodes well for people with Asperger Syndrome (AS).

The first step in deciding whether or not to disclose is to identify the challenges that specifically impact your job performance. Write down how each challenge affects your work. Then note what accommodation is needed. Let’s say, for example, that your challenge is being able to prioritize tasks. The impact of this challenge might be that you spend too much time on non-critical tasks and miss important deadlines. Your accommodation need might be a daily meeting with your supervisor to set priorities.

If you decide to disclose, prepare a strategy in advance. Simply saying something like, “I have Asperger Syndrome and can’t multi-task” is a poor approach because it puts the burden on your employer to find a solution. If you are proactive in suggesting reasonable accommodations, there is a greater likelihood that they will be implemented.

Keep your disclosure statement short, simple and to the point. Do not go into a long explanation of the history of Asperger Syndrome, scientific theories about its cause, or all of the ways that someone can be affected. Instead, summarize the condition in 1 or 2 sentences, state your challenges, and list the specific accommodations that you believe will address them.

For example, Andy explained, “I have a neurobiological condition called Asperger Syndrome that makes it hard for me to remember oral instructions. I need written instructions to learn the proper procedure for this task.” Kelly, who has Nonverbal Learning Disorder, said, “NLD is like having dyslexia when it comes to remembering times and dates. I need someone to review my appointments with me every morning and help me schedule the week.”

Be sure that you disclose to the human resources department in addition to disclosing to your supervisor so that your disability is “on the record.”

Sometimes accommodation requests can be made without disclosing the name of the disability. Developing a repertoire of explanatory statements may be enough to “neutralize” unexpected behaviors and smooth over misunderstandings. For example: “I’m hyper-sensitive to office noise and wearing headphones helps me concentrate,” or “I have a learning disorder that makes it hard for me to remember verbal instructions.”

The decision to disclose is personal and does not guarantee a positive outcome. It can also happen that an individual is simply not able to meet performance requirements, even when accommodations are made. However, there are also many cases when accommodations have resulted in job retention or a transfer to more appropriate positions within a company.

\(^1\) For more information about the Americans with Disabilities Act, visit the Web site of The Job Accommodation Network at www.jan.wvu.edu.

Barbara Bissonnette is the Principal of Forward Motion Coaching (www.ForwardMotion.info) and provides career development and advocacy services for individuals with Asperger Syndrome and NLD. For a free copy of the guide Workplace Disclosure Strategies, please send an email to ForwardMotion@charter.net.

Raising Funds for Speakers

A small group of parents and educators of the Merrimack Valley School District in central NH got together on June 28, 2008, to hold a yard sale. Our purpose was to raise money to bring speakers to our school district to present talks on issues relating to Autism Spectrum Disorders, free of charge to parents and teachers in our district. The day turned out better than expected, and although it threatened rain, people from all over the community came out to support our effort. We were thrilled to see teachers, occupational therapists, speech language pathologists, and parents of kids on the spectrum all eager to buy and support our cause. We raised enough money to hire our first speaker, Robin Lurie- Meyerkopf from AANE, with some funds left over for future events. If you are interested in joining our group, please email Erika Downie at ebdownie@tds.net.
New AANE Connecticut Chapter Co-Directors

Lisa Ricciardi is a life long resident of Connecticut. She and her husband have a 20 y.o. daughter and a 13 y.o. son, a greyhound and 3 cats. Lisa greatly enjoyed her work as an assistant program director for a senior agency. She serves as a board member of the Newtown Fund, a non-profit agency that helps raise funds to support local families in her community. She loves family time and music. Lisa says, “I want to see every school system have a flexible plan in place for our Aspie children, so they can be accepted for their differences, embraced for their uniqueness, applauded for what wonderful contributions they make and will continue to make in this world! I want them to learn lessons that they can understand, based on their own learning style. Of course, this means we need to keep educating the educators—one of our many goals at AANE!” Contact Lisa at 203 426-1774 (home) or lisaraane@gmail.com.

Nancy Hershatter is an early childhood educator who has taught music to children with special needs for many years. She lives in Danbury, Connecticut. Her son, who was diagnosed with AS as a young child, is currently a full-time student at Naugatuck Valley Community College in Waterbury. Contact Nancy at 203 743-0453 or nancyhaane@gmail.com.

AANE Rhode Island Chapter Co-Directors

Barbara Whalen was a founder of AANE. She has provided information, support, referrals, conferences, support and social groups for over 200 Rhode Island families for over a decade. She is delighted that she will now have a new co-director to help her further develop the AANE RI Chapter. Contact Barbara at 401-762-7501 (work) or bwhalen@nricommunityservices.org.

Toby Liebowitz is the mother of two adult sons with special needs. She is an experienced educator specializing in children who are anywhere on the autism spectrum as well as those who have hearing impairments. She is currently working as an educational consultant in both Rhode Island and Massachusetts. She specializes in facilitating open communication between schools and families, to create the best programs for children and young adults. Toby remembers when AANE was just forming and helped her to find her way in the fascinating world of AS. She is excited to have the opportunity to help create an active AANE RI Chapter to help other families. Contact Toby at 401 556-7557. (work) or toliebo@aol.com.

For information on other AANE Chapters, please see our website. You may also contact Robin Lurie-Meyerkopf at 617 393-3824 x 316, or Robin.Lurie-Meyerkopf@aane.org.

Greetings!

Spring brings new life and new activities to the world around us—and also to the adult social programming at AANE. Our LifeMAP individual coaching program continues to grow. In May, we will launch a series of independent living classes generously funded by Autism Speaks. We will also continue to offer our many support groups, an ongoing Book Club, Speaker Series and Anime Club, as well as a variety of Pizza and Game Nights and weekly strolls. Additionally, we will try to offer events and activities that appeal to all of you in our community.

This summer we are also excited about our 2nd Annual Summer BBQ (which will take place June 20th at the Arsenal Park), a return to Spectacle Island July 11th and multiple Red Sox games! Do not forget our Adult Conference in July 18th at Northeastern University, with keynote speaker Ari Ne’eman of the Autistic Self-Advocacy Network.

Remember, we are here to offer support and programming to you our members—please let us know when and how we can be of assistance! Thank you. We look forward to seeing all of you soon!

Sincerely,

AANE Adult Services Team
Jamie Freed, Max Sederer, & Deborah Geheran

Dear Kathryn and Deborah,

So remember a couple months ago we had the police visit our women’s group to talk about personal safety? Well guess who got real-life experience with cops today? Yeah, we were robbed. Which is such a ridiculous idea I almost can't get over it because, you know, this is Wayland. But! The cop said I did everything right! I came home from the grocery and my mom was out but there was a pickup truck I didn't recognize in the driveway. And honest to goodness, if it weren't for that police presentation I would have gone into the house, but I didn't. I went to a neighbor’s and he went into our house and this guy came out with a flimsy excuse about snowplowing or something. He left really fast, and the police came. Luckily with just my mom and I living here we know exactly what he touched—which was a lot—and I may have lost a pair of earrings but that could also be just my own carelessness. They kept asking me to describe the guy and because the Watertown police were understanding I explained about Asperger’s and prosopagnosia—the not remembering faces thing. I don't think they really got it until I mixed up the detective and the police sergeant and couldn't tell them apart! So I might look at some pictures, but luckily our neighbor is 100% on it and can identify him easily. They said he's probably some weird druggie or something.

So anyway just wanted to THANK YOU for arranging that training! It was very very very useful! Also we will definitely be locking our doors from now on even when we're just on a grocery run!

Have a good week, K.
Teaching Autism to Teachers

by CarolAnn Edscorn

I am wearing bright neon green rubber clogs. Is everyone looking at my feet? I prefer to be invisible, but these shoes are not about invisibility. But they are a gift and so I am not invisible today.

It is two years since I disclosed my diagnosis of autism in a public setting. Over the past two years I have traveled around New England and cross country sharing my life in autism. I can no longer hide behind my children, my husband, or the odd character roles that I invented as false fronts for when I ventured into Their World.

I give workshops to educators about life in autism. I attend family support groups and I am on leadership and advocacy boards. I am overweight, over the half century mark, and I am—finally—worthy. I am regularly given gifts by grateful participants. I am cool. Wow.

I wear these bright green shoes, a crocheted sweater, earrings, necklace and a scarf. I keep the gift books near my bed and the art work above my desk. They are just things, objects. They are actually meaningless to me, except I guess the gifts are a sign of love, maybe acceptance. I touch hearts and open minds. I have a Big Hope, an optimistic goal: how can I help just one child?

I did not talk until I was almost 4. Now I make up for that! I did not read until fourth grade. I own 1200 books now. I have been fired. I have offended and lost friends and family. I have cried a lot, and hidden. I share that my IQ was tested at 80 in third grade but tested at 150 in tenth grade as my expressive did not talk until I was almost 4. Now I make up for that! I did not read until fourth grade. I own 1200 books now. I have been fired. I have offended and lost friends and family. I have cried a lot, and hidden. I share that my IQ was tested at 80 in third grade but tested at 150 in tenth grade as my expressive skills caught up with my receptive language.

Turn back the calendar. I am standing in front of 200 parents and educators. I have a new experiment for my seminar. I worry about whether it will work. It is about finding common denominators, increasing empathy, broadening acceptance. Let the experiment begin! I engage the teachers:

Feel your feet. Can you feel your toes? Are you wearing sandals? Clogs? Are there tags or seams? Ties or straps?
Feel your clothing—are there big seams in your jeans? Buttons? How does the fabric feel? Is it itchy or soft? Can you feel your derriere on your chair? (I hear soft embarrassed giggles.) How about your back? Your arms? Can you feel your hair? Do tendrils of hair tickle your neck, your face? Is it pulled back, maybe too tight?

Gaze about you. Look at all the different colors and patterns. What are people around you wearing? Do they have on jewelry? Notice the carpet! The pattern in the ceiling tile—what does it do? Are the lights too bright? Do they flicker? What is happening outside the windows?

Listen to the sounds around you. Can you hear the air conditioning? The traffic outside? The birds? Can you hear the fan in my computer?

Do not forget your feet or that tendril of hair or the breeze from the air conditioner—all those sensations...you have to keep thinking about all of them at the same time!

I have thought long and hard about finding a simple way to make sensory issues real and I have chosen two songs. On the left I have a group singing “Row, Row, Row Your Boat.” On the right I assign “Jingle Bells.” I call out “Remember your feet! Remember your butt!” Confusion sets in. Good. I see worried faces. Good. I get to the last assignment:

“Now turn to someone two rows over and try to carry on a conversation.”

Chaos ensues! It works! They recognize that they cannot talk at all with all of the sensory issues in full force. They respond to my request for quiet. I keep on top of the energy.

“Dear teachers, in your classrooms you have children who cannot possibly filter out all the sensory input, all their emotions—how can they hear you teach?”

There is silence as everyone considers this question. I am only 10 minutes into my presentation and there are tears, thoughtful eyebrows knitted together, pursed lips. I walk among them, these teachers and parents who have come to me to understand their children better. Here I get to be myself, straight out, possibly rude. I address individuals: “That red is too bright for your classroom. Those sparkling earrings are gorgeous. They are all I would look at—and I would not hear your instructions. Great tie, save it for Halloween.”

Persons with autism often look down. That’s when I see them. She is wearing bright yellow clogs. I love those clogs! I invade her space, shooting questions at her. Can I touch them? Are they soft? Can you jump higher in them? Is yellow your favorite color? My questions pile up and she is not allowed to answer because all of my internal computers are hyper focused on her very bright shoes. I suggest she not wear them the first week of school, and then I change my mind. I tell them all to wear something consistent that can help the student identify them, aid the child to feel safe and connected.

In spite of the sensory overload and cognitive challenges, after the talk I stay in the hallways of the convention center sipping coffee. I get more questions, more stories, more tears, lots of thank you’s, and it is so amazing because they got it.

Stand to the side of your students, this makes them feel safer. Speak quietly, with love. Only ask once; let your student process your question without hounding her. They do that for me, calmly waiting for my reply, not finishing my sentences, not condemning my honest blurs.

My mentor approaches me with a smile. “You did it again.”

I think a bit. “Tell me, explicitly and concretely, what did I do?”

“You made them see, you helped them understand. You opened their hearts.”

“This is a good thing?”

“Yes! It is a wonderful thing.”

The next day of the conference, I found a bag hanging on my chair next. My service dog sniffed the bag. Inside were the bright green clogs, a gift from Ms. Yellow Clogs. I immediately put them on. They are so totally not how I see myself but I am so excited. I track down this teacher to thank her, but she shakes her head. “No, thank YOU.” I show her that these rubber shoes do indeed help me bounce higher and she laughs.

I know that I have created Big Hope for her and for the teachers who give me chocolate, earrings, and gifts that reflect
Fellow Aspies

I call upon you, my fellow Aspies,
to awake, and enlighten the human world
with the long-buried truth of Asperger's Syndrome
so that people can learn some new angles on life,
including the doctrines of substance over style.

As you sit in the dark womb
of a flickering planetarium,
call your true self into being.

Let the Orion constellation guide you
on the search through a wilderness
where you dodge ironclad bigots
and solve the hieroglyphics
of everyday communication.

Stay on the search
and you will find those who appreciate
the Aspergian magic you weave
when you take them on a cruise
in the life-like waters of a 3-D picture,
or cut Christmas cookie dough into Kwanzaa shapes,
or re-invent the automobile
to free us from the expensive tyranny of petroleum.

But whatever you do, be assured
that Aspergian tutelage will guide you
into the rebirth of day.

Chris Robbins
**Love Story** (a poem for September 11, 2008)

by Lydia Marie XinZhen Brown

You stood before me shining in my glory
Faces all aglow with joy and sincerity
Full of happiness and love
You were wholly mine, and I was wholly yours
But you all walked away
You forsook me, your father, the Giver of Life
I loved you and gave you my heart
What more could you want?
You sought wealth and power
And five minute highs
Excuses to satisfy the lust you had never had before
You broke my heart
Like a hammer shattering stone
When you walked away, disappearing into darkness
I cried out to you many times
Sometimes you looked back
But you walked further away
You abandoned me and I cry alone
I weep rivers of tears for you
I watched your hearts become diseased and vile
As you stained them with blackest sin
I tore my hair in grief
As you killed millions in my name
I mourned you many times
As your longing and love were sacrificed for Beelzebub
And I carried your casket alone
To be buried in an unmarked grave
I loved each and every one of you dearly
Though you scoffed and threw my words over your shoulder
When you were hurt, I was in great agony
When your cities were destroyed,
a piece of my heart crumbled away
When your cities grew, and with them your evil,
I sprinkled ashes on my head
Every day I saw you stumble further away from me
I reached out to you
But you were deaf
You could not hear me calling to you
You could not hear me crying my heart out
You pretended you still loved me
And brought me false promises and gifts
Moved for a day
Before returning to evil ways
You claimed you were my truest servants
While your knives slit the throats of your brothers and sisters
Eventually, even your lies of being mine stopped
And you scorned my very existence
When I cried out to you
You said it was not real, it was not real
And I wept the more

My son in Arabia grew, and in time
He loved me through a false paradigm
And swore he would kill the infidel for me
Like so many others before him
At his words I wept and tore my hair
For all lies carry within the seed of bitter truth
Now all my children, all of you
Lived mired in false promises
Spoken from the lips of false prophets
And lies spoken from the lips of Shaitan
You blinded yourself to the brilliant light of my truth
And turned to me again however briefly
When with two towers, your confidence fell and shattered
And you lived in fear—o how afraid were you
And I could not look—it hurt too much
To see my children, my sons and daughters, suffering in agony
I loved you wholly
You forsook me
And, inexplicably, I still pour my heart out to you
For you are mine, and I am thine

Lydia Marie XinZhen Brown was adopted from China at 11 months old. She lives in Melrose, MA and is a sophomore at Lexington Christian Academy. She was diagnosed with Asperger’s Syndrome in 2006. Lydia loves to write, sing, and read. She hopes to have her novel published, become an FBI agent, and change the world.

**Rocking**

by Michal Maoz

Moving backward to the south then
Forward to the north
Feeling a sense of calm
Spreading from head to toe
Peace and quiet in my head
Is all I want to know.
Rocking slowly, humming a tune
Looking through a window
Staring at the moon
Wishing,
“If only there will come a day
When all this noise will go away.”
Rocking harder and harder
No peace and quiet
Now humming louder
Looking at the moon
Crying
Another wish went down the drain
Later I’ll try to rock again.

Michal’s book: “The Alien In Me: Poetry by a person with Asperger’s Syndrome” is available online at www.autistic-spectrum.com/TheAlienInMe.
In memory of Margaret S. "Maggie" Betters,  
Mother of Bonnie Betters-Reed  
Betty Bailey & Gary Weiss  
James F. Gemza &  
Norma Montagnino-Gemza  
Mr. & Mrs. Jeffrey Essig & Family  
Carleen & Stanley R. Hall  
Sheila & Karst Hoogeboom  
Mr. & Mrs. David King  
Mr. & Mrs. Andrew King  
Mr. & Mrs. Robert King & Family  
Barbara & Clinton McCoy  
Deborah Marlino & Deborah Merrill-Sands  
Charles T. O'Neill & Mary Ellen Neylon

In memory of Mary Bigwood  
Mary Ellen Maier

In memory of Marshall Cobleigh  
Camille L. Collette  
Virginia N. Esson  
Brenda Sousa  
Three anonymous donations

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& Sharon Zukowski  
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Teresa & Robert Goetzl  
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Sam & Irene Gravina  
Risa Graziano, in honor of Owen's team at
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In honor of Jose Varon & Phyllis Greene
In honor of Mark Jaffe & Joe Kellogg
In honor of Molly Lesnick's 70th birthday
In honor of my son, Connor

Robertta Jaffer
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Charlotte Lebowitz

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David & Carol Lombardo
David H. Long
Christine Long
Louis Lucas
Cheryl Luzinski, in honor of Julia Munroe
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Daniel Macht
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Thank you to Marcy Stuart for her work as Administrator during Lisa Graffeo’s recent absence.

Special Projects

THANK YOU!

A heartfelt THANK YOU to all our generous donors!
Marshfield High School senior Michael Mayes was one of 28 youths sworn in on Sept. 12, 2008, to the Governor’s Statewide Youth Council, a new group of young people handpicked to advise Gov. Deval Patrick on issues facing teenagers. Mayes, 18, is one of two representatives serving a two-year term for Plymouth County. However, he will not only be representing his peers in Plymouth County. Diagnosed with AS, he said he wanted to speak for youths with disabilities. Mayes has been part of a program in the Marshfield schools where he mentors younger students with autism, teaching them how to cook and speak to other people. An avid sports fan, Mike hopes to go into sports management as a coach or a scout after he graduates. He was also an umpire and a pitcher in Marshfield Youth Baseball, plays baseball and football at Marshfield High School, and works summers at South Shore Baseball in Hingham as a coach, teaching 4- to 7-year-olds. Adapted from a Marshfield Mariner news article by Lydia Mulvany, who also took the photo.

Teen Girls Group by Ashley Scott

Over the past few years I have noticed that I am not the only one who sees the world differently. I have recently met and befriended girls around my age with Asperger Syndrome or HFA. These girls are the most wonderful people you could meet. About a year ago I asked my mom if there was a teen group for kids like me, she said there wasn’t and asked me what I had in mind. Then we did some research and mom made some phone calls. One of the calls was to Robin at AANE she said she would help. Next we searched for a space for the group. We got in contact with the Brain-tree teen center and they gave us the ok. Now all we had to do was send out flyers. Soon we started to get phone calls and emails from people wanting to join. We have created a social group where girls with AS/HFA in middle and high school can come and hang out. We brainstorm ideas for the group ourselves and one of the moms brings in materials. Mostly we just talk, and I can say we don’t do the best job staying on topic. We manage through it though. The girls and I work together to find something we all enjoy and pursue it within the group. Some of the things we have done so far include Guitar Hero 3, karaoke, line dancing, and going out for manicures, to the mall, and to lunch. The coolest thing so far was having one of the Patriots’ cheerleaders visit with us. So far there are six girls in the group and we all get along pretty well. Just to make sure things are going okay we have a mentor, Erin Flaherty. She is in her 20s and has AS, we consider her part of the group. She is there to make sure we are safe, having a good time, and doing what we are supposed to. She also participates in all of the activities. We all have a blast in the group and I can see I’m not the only one who benefits from it. We got so many calls from people about the group that my Mom decided to have a Teen Party once a month. That way we can hang out with a wider range of people. The party is co-ed so we can have some experience talking to people of the opposite gender. I’m very glad that my mom helped me start this group. It gives me a feeling of pride and accomplishment.

Above you can see a picture of me and my friends from the group. Our mentor Erin Flaherty is in the back row, far left. On page 30, you can also read a poem I wrote back when I was 12.
We invite you to join us at the 2009 

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Tickets are selling fast, get yours now! 

~Proceeds from the gala and auction to benefit the Asperger’s Association of New England~

Graphic by Julie Betters at JB Design, www.juliebetters.com